

Qualitative Cancer Genetic Counseling Research, Part I: Ethnography in a Cancer Clinic

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This is a report of the experience of several months' ethnographic research by a genetic counselor researcher in a cancer treatment clinic. One goal of the exercise was to directly experience a method of qualitative research known as ethnography, which relies heavily on participant-observation, in an applied clinical setting. Another goal was to explore a previously undescribed research area in the genetic counseling literature, namely, the meaning of cancer and cancer treatment for affected individuals and their support companions. Here we report on a personal account of the experiences of conducting and publishing the research. The preliminary analysis and results of this field experience are published elsewhere (Peters et al. (2001) J Genet Counsel 10(2):151–168.). These initial findings support the feasibility of genetic counselors, who are trained in specific social science methodologies, to conduct qualitative research pertinent to genetic counseling practice.

KEY WORDS: hereditary cancer; genetic counseling; qualitative; behavioral; psychosocial; research; ethnography; anthropology; participant-observation; family.

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INTRODUCTION

This is the report of the experiences of undertaking a small ethnographic study in a cancer clinic at a large, urban medical center with the goal of gaining a new perspective on the experience of cancer treatment for both patients and companions who accompany them to clinic. A collaboration between genetic counselor, anthropologist, and physician was born and matured in the planning, design, implementation, analysis, and publication of the study. In addition, the anthropologist had previously been a cancer patient who experienced treatments similar to those observed in the clinical setting. The physician is an internist and medical geneticist with experience in treating patients with cancer. Thus our ethnographic collaboration also involved the perspective of two "insiders" or "key informants" of the medical setting (Fetterman, 1998). This paper will focus mainly on ethnographic research theory and methodology and on the experiences of conducting this study. Exploration of one theme of physical context of the clinic is used as illustration of the ethnographic method. We discuss the main key findings in a companion paper (Peters *et al.*, 2001).

BACKGROUND

The current study involves utilizing a type of qualitative methodology to explore a little studied area of genetic counseling, namely, understanding the meaning of cancer for those who have had personal encounters with this disease in themselves or in close relatives or friends. Qualitative research has increasingly been used in genetic counseling to capture the complexity of dealing with genetic conditions, to elucidate the processes of genetic counseling, and capture the meaning of human actions (Beeson, 1997). A number of genetic counseling studies have utilized qualitative methods to provide rich descriptions and in-depth understanding of the genetic counseling process and of the people who participate in genetic counseling (Beeson and Golbus, 1979; Chapple *et al.*, 2000; Green *et al.*, 1997; Hallowell and Richards, 1997; Hallowell *et al.*, 1997; Kenen *et al.*, 1997; Lippman-Hand and Fraser, 1979).

As Beeson notes in her overview paper, "Qualitative research is productive because it enables us to discover and document aspects of reality that we cannot necessarily anticipate, and thus to transcend the limitations of our own perspective (Beeson, 1997, p. 24). Qualitative research can explain not only what people do, but *why* they do so" (Blau, 1986). Various qualitative methods (e.g., case studies, open-ended interviewing, life-history studies, focus groups, and other methods) are possible (Denzin and Lincoln, 1994). Ethnography is one of these qualitative methods that has a long heritage in the field of anthropology but which is currently being employed in various other disciplines for the study of applied as well as "pure" research issues.

Ethnography

Ethnography is described on the first page of a noted ethnography text as “the art and science of describing a group or culture as traditionally done by an anthropologist” (Fetterman, 1998). Relying heavily on participant-observation, the strength of ethnographic research is its holistic approach, respect for the empirical world, that is, the everyday lived experiences of people, the potential for offering knowledge of human life and activities in their naturally occurring settings, and the commitment to strive to understand the world and particular experiences in it from the perspective of the group being studied. While the term ethnography is variously described, most definitions share the following features (Atkinson and Hammersley, 1995):

- A strong emphasis on exploring the nature of particular social phenomena, rather than setting out to test hypotheses about them;
- A tendency to work primarily with unstructured data, that is, data that have not been coded at the point of data collection in terms of a closed set of analytic categories;
- Investigation of a small number of cases in detail;
- Analysis of data that involves explicit interpretations of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most.

Culture

All human experiences and behaviors are embedded in culture. Culture may be viewed as the sum of a social group's observable patterns, customs, and way of life. Others define culture as the shared ideas, beliefs, norms, values, and knowledge that people use to interpret experience and generate behavior. Our basic assumptions are that everyone has “culture,” and that we all acquire culture through learning, especially experiential learning. Typically, those in the “dominant culture” are less aware of specifics of their own and other cultures than are members of a minority culture who must learn to operate effectively in both their own and the dominant cultures. Our “cultures” are shaped by the social contexts in which we live and the social identities we adopt. In the current study, the researcher wished to understand the cultures of people attending a cancer assessment and treatment clinic. Individuals coming to the cancer clinic have their own unique social identities that influence their cultural perspective and understandings, for example, they may be middle class, African American, English speaking, religious, elderly, Western Pennsylvanian. And now they have the new social identity of a “person with cancer” which is informed partly by their preconceived notions of what it means

to be a person with cancer and also by their clinic experiences. When they enter the oncology clinic, they also enter clinic culture, which is new to most people.

Broadly defined, whatever the researcher observes people doing in that setting is what defines that culture. Viewed in this behavioral context, the cancer clinic culture involved people coming into clinic for appointments, receiving treatment, passing time waiting, interacting with staff and each other, undergoing evaluations and treatments, and leaving. To understand a group culture at this level, the ethnographer must talk with people and consider their words, symbols, metaphors, and rituals as indications of underlying structures or meaning. The ethnographer attempts to develop increased sensitivity to the ways that culture in this ideational sense influences how people perform the activities appropriate to a given place. The goal is for the researcher to describe what is seen, heard, and understood from within the framework of the group's view of reality. This is known as "the emic perspective" (Fetterman, 1998).

Emic and Etic Perspectives

In ethnography, the emic is the "insider view" and the etic is the "outsider view" of a group's reality (Fetterman, 1998). Whereas the emic perspective most closely approaches the phenomenological world of the group being studied, the etic perspective refers to the external, scientific perspective. Understanding the emic view is important because it helps the researcher understand why people think and behave as they do. Intrinsic to identifying the emic view is the ability to recognize and accept, without preconceived ideas or judgement, the simultaneous existence of multiple realities. These multiple realities may exist within an individual, within different members of the same group, or within the researcher who is expected to hold simultaneously both the emic and etic perspectives. In other words, the investigator immerses herself or himself sufficiently in a situation to access a broad range of the emic perspectives on a given situation while also holding scientific perspective in order to recognize patterns, bring theoretical and conceptual understandings to a given phenomenon or situation, and report these understandings accurately to the outside world.

METHODS

Research Design and Data Collection Issues

One purpose of this fieldwork was to bring the experience of a seasoned cancer genetic counselor together with newly acquired qualitative research methodology in order to elucidate the cancer treatment experience from a different point of view. The project began in response to an assignment for an applied ethnography class.

The research was carried out using an ethnographic methodology, with a primary reliance on participant observation, conducted while the first author was volunteering on a weekly basis in a cancer evaluation and treatment clinic. No other qualitative or quantitative research methods, for example, no formal interviews, in-depth case studies, document review, structured tracking, linguistic analysis, or survey research were conducted during this exploratory phase.

Data from several sources were included, such as watching people; informally chatting with patients, companions, and staff; participating with patients and companions in some informal activities such as eating and use of the kitchen; talking with another volunteer coordinator; reading a brief description of the clinical services in a hospital publication; consulting and reading the literature. The fieldwork lasted for approximately 3 months. The fieldwork yielded exploratory data, with results and conclusions being tentative based on limited experience.

Goals and Research Questions

Framing of hypotheses is not generally undertaken prior to conducting ethnographic fieldwork and this tradition was carried out in this study. The researcher's intent was to stay as open as possible to the scenarios and topics that arose in the clinic setting and to avoid introducing the investigator's own biases, preconceived notions, and agendas as much as possible. The absence of preestablished hypotheses does not imply a lack of direction or purpose in the research. One enters the field with goals in mind in order to avoid aimless activity. The overall goals of this project evolved as follows:

- To learn about ethnographic research through firsthand experience in addition to didactic means and interdisciplinary collaboration with colleagues in anthropology and medicine;
- To collect exploratory data about the experiences of patients and their companions in a cancer clinic in order to better grasp the implications of having cancer;
- To generate questions, hypotheses, and ideas to guide clinical practice and future research.

Field Site

The participant observation was done as a hospital volunteer in the University of Pittsburgh Cancer Institute Comprehensive Cancer Center. In conducting the study, it became apparent that the physical setting has a significant impact on the culture within the clinic and influences the human interactions. The various functions of the clinic were physically separated from each other, each with its

own subculture and subset of participants. This will be addressed in the Results section.

Field Access

The decision to find a formal role in the cancer clinic was made following several frustrating weeks of initial attempts to do fieldwork by simply sitting in the outer waiting room and observing. Becoming a hospital volunteer involved completing a written application and personal interview about one's experience, motivation, and commitment; securing proper hospital identification badges; keeping records of volunteer hours donated; receiving an official volunteer jacket; and attending clinic from 10 a.m. to 2 p.m. each Monday. Being a volunteer gave the researcher a role to fulfill while observing, in other words, enhanced the participant aspect of participant-observation. This proved to be more successful in terms of the data collection process in large part because the volunteer role was more internally congruent with the researcher's personality, cultural, and behavior patterns.

Analysis

Ethnographic analysis occurs through an iterative process of participant-observation alternating with attempts to make sense of what one has seen and heard. "In ethnography, the analysis is not a distinct stage of research. Analysis begins in the pre-fieldwork phase in the formulation and clarification of research problems and continues through the fieldwork, descriptive note-taking, and report-writing, even to the publication process" (Hammersley and Atkinson, 1995). The overarching goal of these activities is to capture the sense of what the people in the clinic are thinking, feeling, and experiencing, that is, grasping the emic perspective.

Brief field notes were taken during or immediately after participant observations. Field notes, sometimes supplemented by audio or video taping, are the traditional means in ethnography of recording observational data, consisting of relatively concrete descriptions of social processes and their context (Hammersley and Atkinson, 1995). These notes were expanded into fuller narratives within one week of each observation period. These expanded field notes were divided into two sections: description and analysis. The descriptive notes capture what was seen and heard in as much raw detail as possible. This is sometimes called simply "listening"; however, it is much more specific in its requirements. The observations in clinic were not entirely random; rather, the descriptive notes were partially informed by the evolving research question, by emerging themes, observer biases and interests, and by chance occurrences as explored in the analytic notes.

Analytic ideas may emerge while making or reading notes, through regular systematic review of material collected thus far, and through insights at unexpected times. It became obvious only in the actual doing that the analytic process involves nonlinear, nondeliberate mental processes occurring at times when the mind is likely to make significant syntheses and connections among various bits of seemingly unrelated material. The analytic portion of the weekly field notes included self-reflection, initial interpretations, evolution of the research question, recognizing patterns of similarity and differences pointing toward broader categorizations and sensitizing concepts, and integrating the observations with published research and theory. The end products might be rich, textured descriptions, explanations, or theory.

Self-reflection is essential to analysis because the person of the researcher is the chief research instrument being used. In volunteering in a cancer clinic, JP was challenged to become more aware of her own issues, biases, privileges, and health in order to know what she was contributing to the observations from her own experiences. This is somewhat analogous to the genetic counselor becoming familiar with his or her countertransference issues that may emerge from and/or impact on client-counselor interactions. Further, the participant portion of participant-observation involves a mutual process of give and take with other people. The researcher is thus conscious of the effect of the research activity on herself as well as on others. The nature of the volunteer's interactions with people in the clinic was influenced in part by that person's personal characteristics and social identities.

To increase the reliability and validity of the findings, the researcher attempts to improve the quality of information by triangulating, that is, comparing areas of overlap in data from several sources. Examples of triangulation from this experience include watching people, overhearing conversations, informally chatting with clinic patients and companions, talking with another volunteer and the volunteer coordinator, talking with one or two of the oncology nurses, and consulting the literature.

PRELIMINARY RESULTS

Initially the field site was experienced by the new participant-observer as fluid, chaotic, dynamic, and confusing. After several observation and analysis cycles, the emergent issues fell loosely into several overlapping, nonexclusive categories. Through this iterative process, the following categories eventually emerged as ones which repeatedly arose in reflecting on observations and experiences in the clinic: physical context; participants in cancer treatment; family and kinship; coping and support; the role of food; healing and meaning of the cancer experience. The theme of physical context is presented in this paper by way of illustration of some of the ways in which meaning can be derived from the raw observations. The remaining themes are explored in depth in another publication (Peters *et al.*, 2001).

Part I: Physical Context

The clinic is the centralized intake point for most cancer patients. The clinic provides initial evaluations, second-opinion consultations, treatment administration, and follow-up care. Other reasons that people attended clinic were to have phlebotomy, biopsy or other medical procedures, for medical decision-making, chemotherapy, pain management, care of treatment-associated complications, and transition from hospital in-patient treatment to out-patient treatment. The goal of the outpatient services is stated as providing patient, family-focused care as a “one-stop” cancer service.

The facility contains 15 examination rooms; two special procedures rooms; three patient and family consultation rooms with round table and chairs; five physician consultation meeting rooms; 16 treatment chairs; 10 treatment beds; and integral pharmacy, laboratory, phlebotomy, and medical records services. Initially, the maze of rooms was bewildering. Gradually it became apparent that there are three main divisions, physically, functionally, and culturally: (1) the exam rooms to the left of the entrance; (2) the chemotherapy area to the right rear; and (3) the oncology staff areas at the back of the clinic off a separate hallway behind the exam rooms.

The chemotherapy area is in its own section on the right side of the cancer center, with four large rooms to treat several patients at the same time. This arrangement seems to foster social engagement for those who are so inclined. A number of private patient rooms at the back of the treatment area are for treatment of patients who receive therapy in a hospital bed, usually for lengthy infusions or because of weakness or frailty. Patients waiting to receive chemotherapy generally were directed to a small waiting room (WR-K) between the treatment area and the kitchen where the volunteer often worked.

The outpatient clinic is held on the left side of the cancer center. The patient hallway has one large and three smaller waiting rooms distributed along the corridor, with patients assigned according to which physician group they were scheduled to see. There are at least five physicians assigned to clinic on any given morning or afternoon. The diagnoses of patients for any given day were determined by the subspecialty of the physicians staffing the clinic at that time. During the times in which the volunteer work for this study was conducted, the patients were mostly those with hematologic, head and neck, skin, or gastrointestinal malignancies.

The clinic field site generally had a light, airy, pleasant, and open feeling. Certain elements of décor in the waiting areas suggested an attempt to make the setting physically pleasant and to normalize the clinic experience by making it appear “homey” in an institutional sort of way, such as using relaxing pastel shades for carpets, walls, seating, and accessories. The larger waiting areas had TV sets, often turned to soap operas or game shows, and/or reading materials and hot beverage selection. Two large fish tanks in the same waiting areas provided a calming diversion. One fish tank carried a submerged sign stating

"get well." Chairs were arranged in conversational groupings instead of lining the walls. A box of toys and games was available for children in WR-K near the kitchen.

The physical layout provided a means of tracking the flow of patients' progress through the diagnosis and treatment processes. Almost everyone spent at least 30–60 min in the large waiting room A near the reception desk, awaiting registration, phlebotomy, other procedures, or awaiting space to open in the smaller waiting rooms. As patients got closer to seeing a physician, they moved to one of the smaller waiting rooms and eventually into an exam room.

The physical setting also set the context for all social interactions in this clinic. A person's literal physical location in the clinical area determined status, function, and purpose of the social interactions that occurred there. The physical layout sometimes segregated groups of people and sometimes facilitated engagement. Most notable was the separation of the medical professionals from the patients and families in the outpatient areas. There was also a separation of different subgroups of patients from each other: Patients receiving chemotherapy treatment were physically separated from those having outpatient visits with their oncologist/hematologist. Most patients in active treatment spent relatively little time in the large general WR-A, spending the bulk of their time either in the treatment rooms or nearby WR-K which served the chemotherapy area exclusively. Even when the same person had both treatment and a physician visit, these happened in different areas of the clinic. This may have served to insulate new patients from people with visible side effects of treatment.

The physical organization also had consequences that seemed to promote subgroup interaction. Because each smaller WR served only patients with certain diagnoses, and only on certain days, patients with similar problems might encounter each other repeatedly at follow-up visits and become acquainted. In the chemotherapy treatment rooms, the arrangement of four chairs in the four corners encouraged potential interaction, whether intentional or coincidental. This is addressed further in the Support section of the Part II publication (Peters *et al.*, 2001).

Learning about the diverse staff may be as daunting to the newcomer as learning to negotiate the physical space. For example, in addition to the oncologists, oncology nurses, and nurse practitioners, there are psychologists and social workers, clinical pharmacists, financial counselors, and dietitians. Learning staff roles is facilitated by the fact that most of the healthcare personnel remain within one section of the facility so that their roles may be inferred.

The oncology department is served by a group of volunteers who each work in a specific clinical site on a certain day each week. A volunteer in this outpatient clinic spends time talking to and observing people as one moves from room to room, sits and chats, gets refreshments from the kitchen, or pillows and blankets from the supply area for patient use. The volunteers are some of the people who

cross over the invisible boundaries between the different sections. Volunteer time is generally divided equally between the chemotherapy treatment area and the outpatient clinic, but not in the oncology staff conference room or back-hall area.

DISCUSSION, QUESTIONS, AND FUTURE DIRECTIONS

Research Role Delineation and Exploration

The role of being a qualitative researcher is one way for a genetic counselor to participate in research that explores some of the deeper psychological and social ramifications of having cancers. However, there were a number of challenges as well.

First, there was the daunting task of learning about new social science research methodologies. This may involve becoming familiar with a new body of social science literature, taking courses, attending continuing education conferences and workshops, and working with knowledgeable collaborators and mentors. The first author did all of the above over a 3-year period before attempting this first exploratory work. Experiential opportunities to participate in research-like simulations were most helpful, following didactic training (Pilarsky and Peters, 1999).

There are also discomforts with being in the researcher role, for example, feeling passive as compared to the active role that most genetic counselors usually play in clinical settings. Specifically, it was a great challenge to "hang out" in clinic waiting rooms without a defined role. Becoming an official clinic volunteer was a useful way of legitimizing the researcher's presence in clinic, thus increasing the researcher's own comfort level.

At times it was a challenge to separate volunteer/participant observer from the genetic counselor roles. This was especially true when genetic counseling clients were also oncology patients attending clinic on volunteer day. For example, a particular adult oncology patient and her mother, whom the first and third authors had been seeing for genetic consultations regarding a rare clinical situation, were also attending clinic for treatment. Both mother and affected daughter were talkative and generally in strong need of physical, economic, social, and psychological support. Both often sought medical reassurances that a volunteer could not give and pressured the first author to deal with genetic counseling and medical questions raised in the cancer clinic setting while JP was acting as a volunteer/observer.

Nevertheless, the blending of roles of researcher and volunteer seems feasible. It was relatively easy to be observant of people and conversations while fulfilling the volunteer role. Making notes during brief periods of privacy was intermittently possible. These brief reminders could then be transcribed and expanded back in the office within several days of clinic without losing too much rich detail.

Ethical Issues in Ethnographic Research

The NSGC Code of Ethics specifies that genetic counselors have responsibilities for the welfare of themselves, their clients, professional colleagues, and to society (Benkendorf *et al.*, 1992). In research, one of the most basic obligations is to do no harm to the research participants, especially those who may be vulnerable due to age, illness, or mental disability. An extension of this principle might be to be aware of the implications of our work on people's lives, both in the research process, and also in our publication of the findings. The ethnographer role carries the responsibility to portray oneself and the people with whom one interacts as a participant observer as accurately and fully nuanced as possible.

The ethnographic researcher enters the field site, as do researchers in every discipline, with biases and preconceptions. These may serve to direct the research into particular areas. However, when uncontrolled or unconscious, these biases also have the potential to erode the quality of a study. To mitigate the impact of these biases, one attempts through the descriptive notes and analysis processes to make one's biases explicit and bring this awareness into the analysis as far as possible. Ideally this self-reflection contributes to the internal validity of the qualitative research project. In this study, the analysis also involved sharing notes devoid of personal identifiers, verbalizing impressions, and brainstorming ideas first among fellow students, and then the authors of this paper.

In participant observation, the researcher assumes a specific role in the culture that is being studied, in this case, that of clinic volunteer. Adopting this volunteer role raised questions of privacy and confidentiality which were addressed in several ways. First, the study design, on-going data collection, and analysis were monitored regularly by the anthropologist who approved the exercise in the context of a class assignment designed to gain practical experience with field work and who acted as an involved collaborator during each stage of the work. Two other sources of information about ethical conduct were sought: consultation with a bioethicist and investigation of regulations. Specifically, we read commentary from the Office for the Protection from Research Risks (OPRR) guides regarding protection of human research participants. The latter is based on federal regulations which help guide Institutional Review Boards (IRBs) and the researcher in the responsible conduct of research (OPRR, 2000).

The OPRR commentary section on privacy and confidentiality suggests several factors that are relevant to the question of IRB approval of such research. First is the extent to which the behavior in question is public. Generally, observations of public behavior, such as observing pedestrians on the street, raises little if any concern about privacy. In the present study, the researcher interacted, as volunteers are expected to do, with patients in quasi-public places, such as waiting rooms and open chemotherapy rooms, never in private examination rooms or outside of the clinic. When occasionally questioned by clinic attendees, she answered openly

about her volunteer status being in addition to work at a school of public health, her status as a student taking classes, and her desire to know what it was like to go through cancer treatment. She restricted conversation to topics appropriate for the surroundings and did not discuss anything that would be expected to cause patients or companions to feel embarrassed or vulnerable. Furthermore, the researcher did not conduct in-depth interviews, which would have potentially revealed more personal or identifying information than they would have ordinarily revealed in a public place.

OPRR regulations conclude that “most observational research, except that involving children and minors, is exempt from federal regulations” (pp. 3–30). They go on to state that “For studies involving adults, current regulations require IRB review only for the most risky observational investigations—those in which two conditions exist: (1) the observations are recorded in a manner that allows the participants to be identified, directly or through identifiers linked to them and (2) the observations recorded, if they became known outside the research, could reasonably place the participant either at risk of criminal or civil liability or cause damage to the participants’ financial standing, employability, or reputation.” Neither of these risky conditions was met in the current study, therefore conditions for exemption were satisfied. Naturally, an IRB-approved protocol would be appropriate if the research were extended further, for example, conducting in-depth interviews that focused on particular identifiable individuals.

Personal Reflections of the Authors

The person of the investigator is the main instrument used in obtaining and analyzing the data in ethnographic research. It is customary for publications resulting from such research to contain enough explicitly subjective information for the reader to have a sense of the investigators and to make judgements about potential biases that may have been introduced. There have even been compilations of realistic accounts of the process of engagement with participants and the personal consequences of conducting fieldwork (DeMarrais, 1998; Larreau and Shultz, 2000). We have extended this tradition here to explicate our personal/professional experiences that probably impacted the process of conducting this qualitative research. These personal impressions are expanded elsewhere in this and the companion paper (Peters *et al.*, 2001) with more detailed observations and analyses.

June

Initially I expected that decades of experience in genetic counseling would have prepared me to do ethnographic research. This proved to be partially true. One advantage was that I was already familiar with medical culture, that is, the structure

of medical settings and roles of various professionals such as physicians, nurses, clinic administrators, and clerical staff. Secondly, genetic counselors generally have a facility for talking with people and putting them at ease while in stressful situations. Also, genetic counseling and oncology deal with some of life's more difficult situations. Helping people negotiate their way through intense medical situations provides a sense of gratification and meaning. There was some sense that my presence as a volunteer may have contributed to a context of caring and healing for some individuals with whom I came in contact. This "healing presence" is not generally highlighted in genetic counseling training, presentations, or publications, although it may well be a key ingredient in the most successful genetic counseling sessions.

There were also unanticipated challenges. At first, actually doing ethnographic observation was extremely uncomfortable. It felt odd and worthless to be sitting around, "doing nothing" as I experienced it from the viewpoint of someone who was often shutting among three clinical sites and two offices. Finding and negotiating the opportunity to become a Cancer Institute volunteer proved to be a perspective-shifting experience. The volunteer activities themselves were pleasing in simple ways: I felt happy and useful to be talking to people while offering jello and ginger ale, juice and pudding, and blankets and pillows. It was a relief to be without the usual professional responsibilities we carry as genetic counselors. The air of lightness helped me realize how much responsibility most genetic counselors usually take on in clinic and to enjoy the break in the usual hectic routine.

My feelings about the volunteer commitment evolved over time. Initially, this volunteer commitment seemed like a large burden in terms of time and energy. Eventually, after several months of volunteering, I realized that I actually was gaining a great deal personally from the experience and that I had been given a rare opportunity to take protected research time as part of my volunteer commitment. This volunteer opportunity was a gift of time to spend with people in the clinic, to become acquainted with some of the clinic staff. It was an occasion to spend unhurried time with patients and their families, a privilege that many genetic counselors might envy and which I missed once the volunteer period was over.

Ten years ago when I first started working with women at risk of developing inherited breast cancer, I came to terms with my own potential for developing cancer by switching in my head from "if" to "when" I might get breast cancer. This "temporarily breasted" status has helped me to identify with women coming for risk assessment, but it did not completely prepare me for the range of feelings I experienced in relation to cancer while volunteering and carrying out participant observation. There was no way to preidentify with having cancer as I had managed to identify with women who had increased cancer risk.

Empathy toward others begins with the ability to feel our own hurts, remorse, sorrow, and grief. After some time as a volunteer, I began seeing and hearing more

expressions of pain, fear, hope, despair, and anger than I had originally permitted myself to notice. I presume that this meant that I was also feeling a lot more pain, fear, and anger about people getting cancer. This dovetailed at several points with my realizations that my own parents were growing older and more infirm as well as with news of cancer diagnoses, recurrences, or deaths in several friends and/or colleagues.

At one point in my volunteer experience, I consciously made a decision to try touching people more, after realizing that I had not been doing so. Initially I had been extremely cautious about touch, in part due to my training and experiences as a genetic counselor and psychotherapist. However, I came to realize that I was in a different role as a volunteer, in a different culture with different norms, one that included touch as one of the ways that people express caring for one another. With time, I could feel myself literally reaching out more fully to patients and families alike.

In sum, I was changed by the experience of conducting this research.

Carol

For me, this collaboration began when June came to talk with me about my applied ethnography course and her own work as a genetic counselor and therapist. The connections between our respective disciplines of anthropology/ethnography and genetic counseling/therapy were striking, as well as the similarities in how we both approached our work.

The collaboration deepened and became more personal when June chose to do her fieldwork assignment for the course at a cancer clinic, and I began to read and comment on her weekly field notes. At a certain point, I told her about my own diagnosis of and experience with breast cancer, including chemotherapy treatment.

Reading and commenting on June's field notes was particularly challenging—painful and yet helpful in further working through my own cancer experience; in many ways it was similar to good therapy. It contributed to my healing.

In helping June to analyze what she was seeing and hearing, as we sat and talked and the ideas flew back and forth between us, I realized how much my skills as an ethnographer and my personal encounter with cancer could combine to contribute to an elucidation of this all too common experience. I could not, though, have done the participant-observation, analysis, and writing on my own. On the one hand, I lack the medical and counseling expertise that June and Wendy brought to the observations and analysis. On the other hand, it was all simply "too close to the bone." The collaborative process was essential.

I too was changed by the experience of working on this project. I think that I'm a better ethnographer because of it. I know I'm better able to accept my life, the experience of cancer included, and to change my life in ways that further my healing and affirm my value and worth as a person.

Wendy

My role in this research was indirect with regard to patient observation, but my reactions were manifold. I served as medical liaison, with administrative responsibility as the Director of the Cancer Genetics Program to help keep June on sure scientific footing within the comprehensive cancer institute. At once, the dichotomy between quantitative and qualitative research initiated an internal wrestling match. One may wonder how it is possible to reconcile specialty training in molecular genetics with an exercise that requires holding scientific hypotheses in abeyance. As a proper scientist, I experienced angst at the thought of collaborating in a qualitative study since I believed that the great successes of modern medicine, including, and perhaps especially, those in clinical genetics, owe largely to adherence to the paradigm of linear cause and effect.

Nonetheless, I was not a complete novice to the field of qualitative research: I had read and critiqued a small part of the literature, and was open to the project out of respect and admiration for June. The idea of transcending our own perspective to make unanticipated discoveries raises images of scientific giants like Copernicus. How often have I seen scientists try (or tried myself) to fit square data into a round hole? If there exists a method of divesting oneself of dogma, be it religious, scientific, social, or intrapsychic, it can only enhance scientific discovery.

During the project, I occasionally did genetic consultations in the clinic facility described, although this was not the main clinical site for cancer genetics consultations. Most cancer genetic consultations are scheduled for nontreatment areas, in part to protect consultants from the feelings and memories that acute treatment clinics can raise. In the treatment clinic, I had consulted with patients undergoing chemotherapy and those enrolled in various research protocols for otherwise untreatable cancer, some living and some dying. I often walked by the waiting area, observing countless people navigating the corridors and doorways with uncertain faces and unsteady gaits, and noticed the "get well" sign in the waiting room fish tank. Recently, while giving a lecture in an unfamiliar hospital, I wondered how I had managed to become so comfortable in a hospital setting. Despite a natural aversion to hospitals which most sane people possess, I had managed to conquer the intensive care unit, the emergency and operating rooms, and the cancer clinic. Reading about the layout of the clinic in this paper, I recognized that the architecturally implemented segregation of patients and clinicians helped to separate me from a barrage of emotions, and to focus on the science of medicine. Patients would be able to see social workers at the designated times and places, and their emotions (as well as mine) could be cubicled, along with their bodies. Although (surely) I addressed some of their emotional needs in consultation, I could escape to the oncology staff areas to consolidate my thoughts and feelings. The separation also provided a survival strategy.

RECOMMENDATIONS FOR FUTURE RESEARCH

There is a need for more qualitative social, behavioral, and psychological research in cancer genetic counseling. While the larger psycho-oncology community tends to focus on issues such as adaptation to cancer, psychological responses to treatment, management of specific symptoms, treatment compliance, health promotion, screening utilization, and staff support, this is not true of the genetic counseling literature. The cancer genetics literature tends to focus mainly on genetic testing for cancer susceptibility and its impact on patients and at-risk relatives. We believe that genetic counselors could broaden our research interests and participation.

Genetic counselors have potential for becoming involved in psychosocial research as primary investigators, and as valued members of the active research team in the role of coinvestigators, as well as being part of the research infrastructure. On occasion, genetic counselors are approached by psychosocial researchers primarily as means of securing a research population. At other times, counselors may share a good deal of their insights and experiences with the researchers as protocols are established and interview guides are being formulated, helping to make them more focused on specific core issues, rather than abstract theories or general literature reviews. Others may spend considerable effort selecting and preparing clients for research participation. While these activities are vitally essential to a successful study, few of these contributions have been reflected in coauthorship, nor do they always effectively inform genetic counseling practice. One solution to the underrecognition of genetic counselors as research collaborators is to have genetic counselors take the lead on projects such as this. This might better ensure that such research and the new understandings we derive from it would reshape our counseling practices to the benefits of both clients and professionals. Continued efforts are needed to provide adequate funding for genetic counselor-initiated research proposals.

Genetic counselors and social scientists have potential to form creative research collaborations in which all parties play active roles. For example, during this pilot ethnography process, the value of multidisciplinary collaboration was again reaffirmed. None of us could have conducted this research solo. The analysis process was tremendously enriched by the dialogue and mutual exchanges of ideas and impressions among the genetic counselor-ethnographer, anthropologist, and medical geneticist. Each of us took away new perspectives and knowledge that will enrich our work in our respective fields of research and service.

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